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Human rights bodies and mechanisms

Report of the Human Rights Council Advisory Committee on the study on the situation of human rights of persons living with albinism

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I. Background

1. In three recent seminal resolutions,[1] the Human Rights Council expressed its concern about the situation of the human rights of persons with albinism. In the first resolution, adopted in June 2013, it condemned attacks against persons with albinism and requested the Office of the United Nations High Commissioner for Human Rights (OHCHR) to submit, at its twenty-fourth session in September 2013, a preliminary report on the ongoing attacks and discrimination against persons with albinism.[2]

2. In the second resolution, adopted in September 2013, the Council requested the Advisory Committee to prepare a study on the situation of human rights of persons with albinism and submit a report thereon to the Human Rights Council at its twenty-eighth session.[3]

3. In its third resolution, adopted in June 2014, the Human Rights Council recommended that the General Assembly proclaim 13 June International Albinism Awareness Day. On 18 November 2014, the General Assembly took note of the Council's recommendation and decided to proclaim 13 June as International Albinism Awareness Day, with effect from 2015.[4]

4. In accordance with its mandate pursuant to Council resolution 24/33, the Advisory Committee, at its twelfth session in February 2014, established a drafting group tasked with the drafting of the report and designated the following experts as members of the drafting group: Mohamed Al Faihani, Laurence Boisson de Chazournes (Rapporteur), Mario Luis Coriolano, Latif Hüseynov, Kaoru Obata and Obiora Chinedu Okafor (Chairperson).

5. The Committee also decided to seek views and input from States and other stakeholders and, to that end, prepared a questionnaire requesting information on the status and treatment of persons with albinism around the world, which was disseminated in April 2014 to States, relevant special procedures, OHCHR field presences, national human rights institutions and non-governmental organizations. A total of 41 responses were received, including 15 from States: Azerbaijan, Burundi, Chile, Denmark, Georgia, Germany, Luxemburg, Mexico, Nicaragua, Paraguay, Senegal, Slovenia, Spain, Swaziland and Tunisia; 9 from national human rights institutions in the following countries: Bosnia and Herzegovina, Denmark, Malawi, Namibia, the Netherlands, Nicaragua, Romania, Rwanda and South Africa; 10 from the following non-governmental organizations: Amis des Etrangers au Togo; Bien-Être des Albinos de Côte d'Ivoire; the Elgon Foundation for Persons with Albinism (Uganda); the Uganda Albinos Association; the Albino Foundation (Nigeria); the Chinese Organization for Albinism; ALBA – Asociación española de ayuda a personas con albinismo (Spain); Genespoir (France); the Albinism Fellowship of Australia; and NOAH Albinismus Selbsthilfegruppe (Germany); and 7 from OHCHR, treaty monitoring bodies and special procedures: OHCHR in Occupied Palestinian Territory; OHCHR Regional Office for Southern Africa; OHCHR/United Nations Organization Stabilization Mission in the Democratic Republic of the Congo (MONUSCO);

[1] See Human Rights Council resolution 23/13 on attacks and discrimination against persons with albinism; Human Rights Council resolution 24/33 on technical cooperation for the prevention of attacks against persons with albinism, and Human Rights Council resolution 26/10 on International Albinism Awareness Day.

[2] Report of the Office of the United Nations High Commissioner for Human Rights on Persons with albinism, 12 September 2013 (A/HRC/24/57), ("the OHCHR report").

[3] Human Rights Council resolution 24/33, para. 1.

[4] See A/C.3/69/L.35/Rev.1.

OHCHR/Opération des Nations Unies en Côte d'Ivoire (ONUCI); OHCHR/United Nations Integrated Peace Building Office in the Central African Republic (BINUCA) (relating to Burundi); the Subcommittee on Prevention of Torture and other Cruel, Inhuman or Degrading Treatment or Punishment; and the Special Rapporteur on extrajudicial, summary or arbitrary executions.

6. Building on the facts and findings contained in the OHCHR report, the present study first provides an overview of the various obstacles faced by persons with albinism to the full enjoyment of their human rights, and includes the type and severity of the human rights violations involved. Second, it summarizes actions taken at the international level and by OHCHR in response to the issue. The third and final part recommends further initiatives for addressing some of the key problems identified in the first part.

7. On 24 September 2014, the Rapporteur of the Advisory Committee's drafting group participated in an expert meeting on albinism organized by OHCHR in collaboration with the Organisation Internationale de la Francophonie. The meeting brought together experts from international and regional human rights mechanisms and participants from civil society. It was an opportunity to hear the testimonies of persons with albinism and to listen to their proposals on the way forward at the domestic, regional and international levels. The present study has benefited greatly from the expert meeting.

II. Albinism, special needs and human rights challenges

A. Albinism and special needs

8. Albinism is a rare, non-contagious, genetically inherited difference present at birth. In almost all types of albinism, both parents must carry the gene for it to be passed on, even if they do not have albinism themselves. The condition is found in both sexes regardless of ethnicity and in all countries of the world. Albinism results in a lack of pigmentation (melanin) in the hair, skin and eyes, causing vulnerability to the sun and bright light. As a result, almost all people with albinism are visually impaired and are prone to developing skin cancer. There is no cure for the absence of melanin that is central to albinism.[5]

9. While numbers vary, it is estimated that in North America and Europe 1 in every 17,000 to 20,000 people have some form of albinism. The condition is much more prevalent in sub-Saharan Africa, with estimates of 1 in 1,400 people being affected in Tanzania[6] and prevalence as high as 1 in 1,000 reported for select populations in Zimbabwe and for other specific ethnic groups in Southern Africa.[7]

10. Persons with albinism have special needs. An advocacy report of the International Federation of the Red Cross and Red Crescent Societies (IFRC) identified those needs as follows:

(a) Security;

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[5] The definition of albinism comes from A/HRC/24/57, para. 10.

[6] Under the Same Sun, "Frequency of Albinism/Rates of Occurrence: North America, Europe, Africa and Tanzania"; see also, Under the Same Sun, available from http://www.underthesamesun.com/sites/default/files/Frequency%20of%20Albinism.pdf; and "Children with Albinism & the Right to Health, summary report on Tanzania with implication for other parts of sub-Saharan Africa" (2012), p. 2, available from http://www.ohchr.org/Documents/Issues/Children/Study/RightHealth/UndertheSameSun.pdf.

[7] World Health Organization, Epidemiologic data on albinism from a public survey in African countries, 2006.

(b) Help with reintegration into society after displacement or time spent in hiding;

(c) Health education on how to prevent skin cancer;

(d) Protective clothing;

(e) Optician services;

(f) Assistance in participating in mainstream primary and secondary education;

(g) Vocational training to maximize the chance of indoor work out of the sun.[8]

11. While the IFRC report focused on the Great Lakes region of east Africa, those needs, or at least some of them, may be considered to reflect the collective experience of persons with albinism.

B. Rights to life and security of person

12. With respect to security, grave concern has been expressed by the Human Rights Council about "attacks against persons with albinism, including against women and children, which are often committed with impunity."[9] Such attacks involve the violation of fundamental human rights.

13. As mentioned by six special procedure mandate-holders, persons with albinism face dehumanization because they "are regarded as ghosts and not human beings who can be wiped off the global map … [they are] the target of many false and harmful myths in several countries, especially in the African region."[10]

14. The OHCHR report states that "in some communities, erroneous beliefs and myths, heavily influenced by superstition, put the security and lives of persons with albinism at constant risk. These beliefs and myths are centuries old and are present in cultural attitudes and practices around the world."[11] The belief that the body parts of persons with albinism possess magical powers that can be used to gain wealth and prosperity and/or to gain power via winning elections are some of the reasons for the killing of, and attacks against, persons with albinism.

15. Violence against this vulnerable group takes various forms, including the killing of, and attacks against, persons with albinism with a view to using their body parts for ritual purposes. Arising from the attacks and the use of body parts is the trade of organs linked to trafficking in persons and the sale of children, infanticide and abandonment of children.[12]

16. It is reported that, as of October 2014, over 340 attacks against persons with albinism, including 134 killings, have been recorded in 25 countries.[13] Non-governmental organizations working in the field note that the number of ongoing attacks is higher than

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[8] International Federation of Red Cross and Red Crescent Societies, "Through albino eyes: the plight of albino people in Africa's Great Lakes region and a Red Cross response" (2009), p. 17.

[9] Human Rights Council resolution 24/33, preamble.

[10] Press release by several special procedure mandate-holders , "Not ghosts, but human beings … persons with albinism" (4 May 2013), available from www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=13294&LangID=E.

[11] A/HRC/24/57, para. 15.

[12] Ibid., para. 18 .

[13] See Under The Same Sun, "Reported attacks of persons with albinism (PWA), Summary", available from www.underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%201%20page_0.pdf.

that reported, but that data-gathering is difficult owing to the secretive nature of witchcraft, which serves as the context of most ritual attacks against persons with albinism.

17. On 15 May 2014, the former United Nations High Commissioner for Human Rights issued a press statement in which she called for increased protection for people with albinism after the murder of a 40-year-old woman with albinism in north-western Tanzania three days earlier. On 27 May 2014, the Working Group on the Rights of Older Persons and People with Disabilities in Africa also issued a press statement condemning that specific killing.

18. Since then, seven further attacks have been documented in Tanzania, between August 2014 and January 2015, including one murder, two cases of survivors with severe limb mutilation and the disappearance of a 4-year-old girl. The killing of a 25-year-old woman was reported in Malawi in November 2014 and another killing, of a 27-year old man, was reported in Burundi in December 2014. The circumstances in which the attacks took place reveal the severity of attacks against the group. The following are some examples:

(a) On 5 August 2014, Pendo Sengerema, a 15-year-old girl, was brutally attacked at her home in Kaliua District, in the Tabora Region of Tanzania. Three assailants with machetes hacked off her right arm just below the elbow. According to reports, her family could not scream for help as they were threatened with death by the attackers, who later disappeared with Pendo's arm;

(b) On 16 August 2014, two unidentified men entered the home of Munghu Masaga, a 35-year-old woman with albinism and the mother of seven children, in Buhekela village, in Igunga District, also in Tabora region of Tanzania. Before chopping off her left arm and escaping, attackers killed Munghu's husband as he tried to protect his wife. Two of their children sustained minor injuries;

(c) On 12 November 2014, a 25-year old woman with albinism by the name of Violet Kanyama was found dead in the garden of a school near her home in Gawani village, Mulanje district, Malawi. Her body was recovered with both arms and legs missing.

19. These latest attacks underscore the urgent need for States to adopt specific measures to protect and preserve the rights to life and security of person, and the right not to be subjected to torture or ill-treatment. Persons with albinism must be provided with safe and secure spaces where they are able to live dignified lives, free from the fear of being attacked.[14]

20. The Tanzanian police response to the attacks in August 2014 has been reported as adequate, with several arrests made, and a special task force has been set up by the Office of the Attorney General to investigate and prosecute the cases. Those welcome responses are ongoing and it is therefore premature to comment on their impact. Meanwhile, civil society groups have made a clarion call to the Tanzanian Government to enlarge the scope of investigation to unearth the black market in organs associated with the attacks and prosecute clients of the trade. Civil society actors also urged the relevant authorities to introduce effective regulation of the activities of traditional health practitioners. The practitioners, who reportedly practise witchcraft and are revered by many for their perceived supernatural powers and ability to carry out magic, have been mentioned as key players.[15]

[14] One of the recommendations of the Organisation Internationale de la Francophonie/OHCHR Expert Meeting on Persons with Albinism, held in Geneva on 24 September 2014.

[15] See Organisation Internationale de la Francophonie/Office of the High Commissioner for Human

C. Right to an adequate standard of living and other fundamental rights

21. The situation of persons with albinism who have gone into, or have remained in, hiding in the wake of attacks against them, is worrisome. For instance, according to information received by OHCHR, hundreds of children with albinism have been living in appalling conditions in 13 centres for displaced children and adults with albinism in Tanzania, after being abandoned by their families or fleeing their homes further to a spate of killings and attacks against them. Some of the centres are administered by the Government while others are owned by faith-based organizations.

22. Further, according to information received, the centres are overcrowded and the health and hygiene conditions are very poor . In addition, owing to very limited human and financial resources, teaching and learning materials are almost non-existent. Health-wise, there have been worrisome reports of skin cancer at various stages, which is visible on many of the children with albinism living in the centres, partly owing to the lack of awareness amongst staff as well as a lack of basic health information on self-care for the persons with albinism themselves. Sexual abuse has been reported in some of the centres.

23. In a press release of 15 May 2014, the former High Commissioner also expressed concern about the situation of children with albinism living in the centres. She called on the Tanzanian authorities to take urgent measures to assess and address the situation in the centres, including allegations of sexual harassment and abuse, and the poor living conditions. She added that staff working with people with albinism should be trained on their special needs, in particular with regard to basic preventive measures to avoid skin cancer. In August 2014, a United Nations mission visited two of the centres and expressed concern that the centres reinforce segregation of persons with albinism and separate children from their families.[16] There is therefore an urgent need to look into long-term solutions to reintegrate the children into their communities, avoiding over-reliance on institutions as safe places for children[17].

24. Another example is Burundi, where, after a spate of killings and attacks registered from 2008 to 2012, persons with albinism were accommodated in police stations and houses nearby to guarantee their safety. An assessment of displaced persons with albinism in the Northern Province of Kayanza, in Musongati and in Gitega, recently conducted by the OHCHR field presence, shows the precarious security situation of some of them and the negative impact of the measure on the right to an adequate standard of living.

25. Those concerns were reiterated by the Human Rights Committee in its 2014 concluding observations, requesting Burundi to continue its efforts to protect persons with albinism and to find lasting solutions to their situation.[18]

Rights, outcome report of the Expert Meeting on Persons with Albinism: Violence, Discrimination and Way Forward, 24 September 2014 (see footnote 15), para. 21.

[16] The joint mission from OHCHR and the Resident Coordinator's Office in Tanzania visited Buhangiya Primary School in Shynyanga District, which houses 174 children with albinism and Mitindo Primary School in Misungwi District, which houses 45 children with albinism.

[17] The Committee on the Rights of the Child included a reference to those centres in the list of issues on Tanzania adopted on 27 June 2014 (CRC/C/TZA/Q/3–5), also mentioned in para. 53 of the present report. This is also a recommendation from the Expert Meeting: see outcome report of the Expert Meeting on Persons with Albinism, 24 September 2014 (see footnote 15), para. 73.

[18] CCPR/C/BDI/CO/2; see also para. 55 of the present report.

D. Discrimination against persons with albinism

26. Security concerns and associated displacement of persons with albinism are linked to the overall issue of discrimination. The OHCHR report expressed "its grave concern at the severity of the human rights violations committed against persons with albinism in many countries, including the multiple and intersecting forms of discrimination they, particularly children and women, face."[19]

27. Those various forms of discrimination are evident from the "nasty, brutish and short" lives of persons with albinism: if they survive infanticide at birth, they face a constant threat of physical attacks. Should they survive those physical threats, they are unlikely to be educated, owing to the absence of reasonable accommodation for their poor eyesight. A lack of education leads to unemployment or employment outdoors in the sun, where they are vulnerable to developing skin cancer. Skin cancer remains a life-threatening condition for most persons with albinism under the age of 40.[20]

28. All forms of discrimination affecting persons with albinism are interrelated, and there is an inextricable link between discrimination and poverty. "The right to education of persons with albinism, for instance, is adversely affected by the vision impairment they suffer from. A poor education, in turn, affects their right to an adequate standard of living, consigning many persons with albinism to poverty."[21] As a result, the economic and social rights of persons with albinism are disproportionately affected by various types of poverty.

E. Impunity

29. Discrimination encountered by persons with albinism also negatively impacts access to justice.

30. There are little data available on the legal treatment of cases of violence against persons with albinism.[22] Where there is information, it is reported that persons with albinism are discriminated against throughout the whole judicial process. It is reported that law enforcement authorities and some members of the judiciary tend to share the same superstitious beliefs entrenched in the communities, including and not limited to, considering persons with albinism as subhuman beings. Procedural fairness including informing the victim of attack about the trial process, preparing him or her for trial and providing him or her with legal representation or access to the prosecutor are all reportedly impaired by subsisting prejudices against the victim as a person with albinism. In addition, erroneous beliefs about albinism, including inadequate knowledge about their condition, for instance knowledge of the visual levels of persons with albinism, has also been reported to negatively impact the weight ascribed to the testimony of victims of attack. Further, corruption and shortcomings in the resources of the justice system fail to translate initial police action into concrete results in the fight against impunity. Such factors effectively create significant obstacles in access to justice for persons with albinism.

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[19] A/HRC/24/57, para. 84.

[20] For example, one epidemiological study estimated that fewer than 10 per cent of persons with albinism in Tanzania survive to age 30, and only 2 per cent were expected to reach age 40. See Andres E. Cruz-Ingo et al., "Albinism in Africa: stigma, slaughter and awareness campaigns", *Dermatologic Clinics*, vol. 29, No. 1, pp. 7981 (2011) (citing J. Luande et al., "The Tanzanian human albino skin", *Cancer*, vol. 55, p. 1823 (1985)).

[21] A/HRC/24/57, para. 71.

[22] Ibid., para. 50.

31. The challenges persons with albinism face in having their cases brought to justice are grounded in the vulnerability of the population. They include

> the fear of further attacks, reprisals or further stigmatization; difficulties in finding witnesses owing to the ostracism they face within their community and, frequently, the involvement of family and community members in the attacks; the lack of awareness of legal rights; the lack of financial resources; the inadequate capacity of the judicial system to address such cases; the lack of legal aid and adequate legal representation; the lack of knowledge of or confidence in the law enforcement and justice systems.[23]

32. Without effective and affordable access to justice, persons with albinism are unable to adequately claim their rights and contest the human rights violations which they are subjected to.[24] As a result, no type of redress is available to victims, even in the form of medical and psychological support.[25] To date, it is reported that most assistance to victims in the form of medical and psychological support has been provided exclusively by non-governmental organizations.

33. The link between poverty and witchcraft is also a matter of concern and has been explained in the following terms:

> As is the case with witchcraft accusations against women, the elderly and children, muti[26] murders of persons with albinism appear to follow patterns of poverty, misfortune, tension and conflict in societies. Attacks may originate from tense social relations, where no effective or social alternative exists to release or explain such tension. Lack of access to basic resources, education and basic health services correlate with such human rights abuses. These spiritual explanations act as a way of justifying life's misfortunes, hence, maintaining social order. It is, predominantly, the most vulnerable and marginalized groups in society who are accused of witchcraft, because they are either least able to defend themselves from attack and are, therefore, easy targets. Furthermore, as they are considered of little value to society, they consequently become a burden [sic] in times of hardship.[27]

34. States have an obligation to criminalize, investigate and prosecute perpetrators of crimes affecting persons with albinism. That is even more critical given the heightened vulnerability of persons with albinism. The strengthening of the legal response to killings of, and attacks against, persons with albinism will also serve as a deterrent.

F. Women and children

35. The OHCHR report mentions that "women and children with albinism are particularly vulnerable as they are exposed to intersecting and multiple forms of discrimination. In addition, children are particularly targeted for ritual killings and women with albinism are sometimes victims of sexual violence."[28] That is because there is the

[23] Ibid., para. 53.
[24] Ibid., para. 70.
[25] Ibid., para. 55.
[26] Muti is a word used in Southern Africa to refer to magic that enables people to gain power or wealth.
[27] The Witchcraft and Human Rights Information Network, "Exploring the role of Nollywood in the Muti murders of persons with Albinism" (16 August 2013).
[28] A/HRC/24/57, para. 74.

belief in some communities that having sex with a person with albinism can cure HIV/AIDS.[29]

36. Women who give birth to children with albinism are particularly exposed. They are often rejected by their husbands, accused of adultery and blamed for giving birth to children who are perceived as a curse, misfortune or a cause of shame for the family.[30]

37. In her opening remarks at a press conference during her mission to Nigeria in March 2014, the former United Nations High Commissioner for Human Rights alluded to the specific discrimination faced by persons with albinism and the extra vulnerability faced by children with the condition. She stated "One group at particular risk are the some 800,000 children among the 2 million people living with albinism in Nigeria. Many of them are not in school because of visual impairment, discrimination from other children, and social exclusion as a result of their skin colour."

38. The 2014 annual report of the Special Representative of the Secretary-General on Violence against Children identified children with albinism as particularly vulnerable. The report explains that children with albinism are

> at high risk of abandonment, stigmatization, and marginalization as a result of their appearance, and due to disability factors associated with their condition, such as impaired eyesight and sensitive skin (...). Social and structural discrimination condemns these children to a position of extreme vulnerability. Children with albinism are exposed to severe incidents of violence, mutilation and murder. At times they become the target of witchcraft accusations, leading to the use of their body parts for ritual purposes. Children who survive such attacks are left with serious and long-lasting health and psychological consequences, and the development of their full potential is compromised for life. Driven by fear and superstition, incidences of violence are largely met with silence and indifference. They are rarely reported or followed by investigation or prosecution. Overall, there is a pervasive culture of impunity.[31]

G. Violence and discrimination against persons with albinism: a global phenomenon?

39. While it has been reported that persons with albinism globally face discrimination and stigma,[32] information on cases of physical attacks against persons with albinism is mainly available from countries in Africa. It is important to reiterate the point made in the OHCHR report that any real or apparent focus on Africa—whether in the present report or the issue generally— is explained by the fact that, to date, all reported cases of ritual attacks have come from that region.

40. The manner in which discrimination faced by persons with albinism manifests itself, and its severity, vary from region to region. In the western world, including North America, Europe and Australia, discrimination often consists of name-calling, persistent teasing and bullying of children with albinism.[33] In those regions, the substance of discrimination is

[29] This phenomenon has been exposed by various NGOs working in Burundi, Côte d'Ivoire, Kenya, Namibia, Tanzania and Zimbabwe.

[30] Outcome report of the Expert Meeting on Persons with Albinism: Violence, Discrimination and Way Forward, 24 September 2014 (see footnote 15), para. 15.

[31] A/69/264, paras. 34–37.

[32] A/HRC/24/57, paras. 2 and 65.

[33] See Under the Same Sun (UTSS), www.underthesamesun.com/; see also Asociación de Ayuda a

entrenched misconceptions and misunderstanding about albinism, notably perpetuated by the media and popular culture, which consistently portray persons with albinism in a negative light.[34] Given the rarity of albinism in those regions (an estimated 1 in 17,000 to 20,000) the media and popular culture are major sources of information on the condition for the majority. Therefore, unless specific albinism awareness-raising is conducted by support groups and civil society, such discrimination is unlikely to be brought to light.

41. Persons with albinism face more severe forms of discrimination and violence in those regions where the majority of the general population are relatively dark-skinned. The degree of contrast in pigmentation between the majority and the person with albinism in a community tends to correlate positively with the severity and intensity of discrimination faced by persons with albinism. In other words, a greater degree of contrast in pigmentation often gives rise to a greater degree of discrimination. That appears to be the case in some sub-Saharan African countries where albinism is shrouded in myth and dangerous and erroneous beliefs.

42. Little information is available from other regions such as Asia, South America and the Pacific etc. However, some reports indicate that in China and other Asian countries, children with albinism face abandonment and rejection by their families. A recent epidemiological study of persons with albinism from a specific tribe in Pakistan explains the multi-layered human rights problems faced by persons with albinism, including lack of understanding of albinism, social rejection, medical and psychological problems, as well as confinement to poverty.[35] Reliable testimonies received from Mumbai, India, also indicate that persons with albinism tend to be viewed as cursed on account of their appearance. That perceived curse is considered contagious by some, such that persons with albinism are effectively ostracized and isolated from and by mainstream society. Such isolation has been reported to occur even when persons with albinism are moved into special schools such as schools for the blind owing to their visual impairment. Such treatment even within the community of persons with disabilities shows the pervasiveness of discrimination against persons with albinism.

43. Given the fact that evidence such as the above has only come to the fore in the last year, the absence of information on other regions should not be interpreted to mean that there is no problem of discrimination, stigmatization and violence in those regions. Rather, there should be a general presumption that there are human rights issues facing persons with albinism in each region. That presumption can be rebutted by targeted studies in the near future. Lack of sufficient knowledge remains a significant barrier to tackling discrimination, stigma and violence.

III. Responses: successes and subsisting challenges

A. Advocacy

44. The documented reports of ritual killings of, and attacks against, persons with albinism, and the many more undocumented acts of violence and discrimination they face,

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Personas con Albinismo (ALBA), Spain, see www.albinismo.es.

[34] In popular culture, particularly in literature and in film, persons with albinism are portrayed as villains, demons, ghosts, freaks of nature, mystical anomalies or village idiots.

[35] See Azam Jah Samdani and Bahram Khan Khoso, "A unique albino village of Bhatti Tribe in rural Sindh, Pakistan, with oculocutaneous albinism manifestations: an epidemiological study, *Iranian Journal of Dermatology*, (Iranian Society of Dermatology, 2009), pp. 42–46. See also "Feature: Nepal's albinos caught between reality and myth", (Shanghai Daily.com, 9 October 2014).

undoubtedly call for a more active promotion of, and advocacy for, the rights of persons with albinism. Without strong advocacy it will be difficult to achieve concrete results at the international and regional levels.

45. One example of such advocacy is the initiatives recently taken by OHCHR to raise awareness and promote the protection of the rights of persons with albinism, thus increasing the visibility of violations against the group, which until then had received little attention from the international community. The High Commissioner's voice, through press statements; side-events on the margins of Human Rights Council sessions; expert meetings such as that mentioned in paragraph 7 of the present report; and online public information campaigns; are all tools that can be used to increase understanding and raise awareness of albinism, all of which OHCHR has been successfully using with the aim of achieving a consensus among States on the importance of promoting and protecting the rights of persons with albinism and combating impunity for attacks against them.

46. Another advocacy tool that can be used to raise awareness of the human rights situation of persons with albinism is through engaging artists in the endeavour, as they can reach out to a greater number of people through their voices and work. In that regard, it is noteworthy that, on 5 December 2013, Salif Keita, musician and advocate for the rights of persons with albinism, performed at the Palais des Nations in Geneva.

47. In addition to advocacy at the international level, it is equally important to engage in advocacy at the regional level. Here the role of civil society organizations becomes very important and their engagement with human rights mechanisms at regional level needs to be enhanced with a view to stimulating regional responses to key human rights concerns. Representatives of civil society organizations conducting advocacy on behalf of persons with albinism in African countries for instance, can be supported to participate in platforms such as the Non-governmental organization (NGO) Forum in Banjul or in discussions on cooperation with the African Union organs, as was done by OHCHR in 2013.

48. At the national level, there are only very few instances of such advocacy that can be referred to. For instance, the Human Rights Component of the United Nations Operation in Côte d'Ivoire (ONUCI) has strengthened the operational and institutional capacities of one of the albinism groups in the country, Bien-Etre des Albinos de Côte d'Ivoire (BEDACI), through a quick impact project, and has conducted training on documentation techniques of human rights violations.[36] The Human Rights Component of the United Nations Office in Burundi (BNUB) has for its part been monitoring the situation of people with albinism in the country. Human rights advisers can also be another good option for advocacy as they can be instrumental in promoting a more active role of key stakeholders in the protection of persons with albinism, including the United Nations Country Team, the national human rights institution and the relevant authorities.

B. Assistance to victims

49. The United Nations Voluntary Fund for Victims of Torture, managed by OHCHR, is a concrete way to care for the survivors of attacks and their family members. It provides direct assistance to victims of torture and their family members through grants awarded to non-governmental channels of assistance, including NGOs, rehabilitation centres, associations of victims and family members. In 2014, the Fund awarded a grant, through its

[36] See ONUCI replies to the Advisory Committee questionnaire, available from www.ohchr.org/EN/HRBodies/HRC/AdvisoryCommittee/Pages/AttacksAgainstPersonsWithAlbinism.aspx.

intersessional emergency procedure, to the non-governmental organization Under The Same Sun in Tanzania, for the provision of medical rehabilitation (prosthetic work) and psychological assistance to several identified victims, both men and women, mutilated during attacks. The financial support to that victim-focused project has been renewed by the Fund for 2015 so as to extend the specialized assistance provided by the project to an additional number of victims and their families.

C. International human rights mechanisms

50. Various human rights mechanisms, notably the Human Rights Council, including the universal periodic review and treaty monitoring bodies have addressed the situation of persons with albinism. Some examples of the recommendations made in 2014 are listed below.

51. In April 2014, during the review of Côte d'Ivoire under the universal periodic review (UPR), Spain expressed concern regarding discrimination against persons with albinism and made the following recommendation which enjoyed the support of the country: "To take concrete measures to protect the rights of people with albinism, in accordance with the recommendations made by the Office of the High Commissioner, and raise awareness among society about their situation."[37]

52. Also in April 2014, during the UPR of the Democratic Republic of the Congo, Guatemala shared the concern of the Committee on Economic, Social and Cultural Rights[38] about the killing of persons with albinism and the use of their organs for witchcraft ceremonies. The following recommendation, which enjoyed the support of the country, was made: "To combat all forms of discrimination against persons with albinism".[39]

53. In June 2014, the Committee on the Rights of the Child, in its list of issues for Tanzania, requested the State Party to:

> indicate whether a comprehensive strategy has been put in place to stop the gross violations of the right to life, survival and development of children with albinism in the State party. In particular, please provide precise and detailed information on: (a) The educational and awareness–raising measures undertaken and currently being conducted by the State party to overcome traditional beliefs causing stigma and discrimination against children with albinism leading to killings and a wide range of violence against them; (b) The measures adopted to prevent, investigate and punish crimes against children with albinism, including the use of their body parts for witchcraft and to provide redress to victims; (c) The measures taken to improve the living and safety conditions in the centres where these children are placed, to ensure that they are not subject to degrading treatment or abuse in these centres, to adequately train staff and hold them accountable for any professional misconduct, and to ensure regular supervision and control of these centres; (d) Any pilot initiative aimed at preventing the placement of these children and/ or to encourage the reunification of children with albinism with their families, when possible.[40]

54. In its concluding observations on the periodic report of Swaziland of July 2014, the Committee on the Elimination of Discrimination against Women expressed concern

[37] A/HRC/27/6, recommendation 127.103.
[38] E/C.12/COD/CO/4.
[39] A/HRC/27/5, recommendation 134.47.
[40] CRC/C/TZA/Q/3-5, para. 8.

at the gruesome murders of women and girls with albinism, whose body parts are harvested for rituals. The Committee is particularly concerned at reports that, in the past, perpetrators of such murders were prosecuted for less-serious crimes, such as causing grievous bodily harm, and therefore received lenient sentences upon conviction. The Committee recommends that the State party urgently establish a national register of persons with albinism and provide protection to women and girls with albinism. The State party should ensure that all complaints relating to violence against women and girls with albinism are effectively investigated and perpetrators prosecuted and punished with appropriate sanctions upon conviction.[41]

55. In October 2014, in its concluding observations on the periodic report of Burundi, the Human Rights Committee requested the State Party to continue its efforts to protect persons with albinism against any form of discrimination, including physical attacks, and to find sustainable solutions guaranteeing their access to health care, social services, employment and education.[42]

56. The Human Rights Council, in June 2014, adopted resolution 26/10 without a vote, recommending that the General Assembly proclaim 13 June as International Albinism Awareness Day. The date is symbolic, as the first global resolution on attacks and discrimination against persons with albinism was adopted by the Human Rights Council on that date in 2013. The initiative provides a platform through which stakeholders can raise public awareness on this pressing human rights issue. The resolution recognizes the importance of increasing awareness and understanding of albinism in the fight against global discrimination against, and stigmatization of, persons with albinism. The day was called for by some NGOs serving persons with albinism, particularly those based in countries were there have been records of attacks. It has also been welcomed by an overwhelming majority of a cross-regional listing of NGOs serving persons with albinism worldwide. Following the recommendation made by the Council, on 18 November 2014, the General Assembly proclaimed 13 June as International Albinism Awareness Day.

D. Regional human rights mechanisms

57. As a very significant step at the African regional level, on 5 November 2013, the African Commission of Human and People's Rights adopted resolution 263 on the prevention of attacks and discrimination against persons with albinism. Among other things, the resolution requires member States to include in their reports to the African Commission information on the situation of persons with albinism, including good practices in protecting and promoting their rights.

58. Also in November 2013, at its twenty-second ordinary session held in Addis Ababa, the African Committee on the Rights and Welfare of the Child considered the issue of albinism and adopted a Declaration on Ending Discrimination and Violence against Girls in Africa, in which the situation of children with albinism was addressed.

E. Challenges

59. Despite the above strides, there remain a number of challenges to a more active engagement with human rights mechanisms. They are detailed below, amongst other challenges to ensuring an adequate response to the issue:

[41] CEDAW/C/SWZ/CO/1-2, paras. 22–23.
[42] CCPR/C/BDI/CO/2.

(a) Limited knowledge of the issue and its impact on the enjoyment of human rights by persons with albinism;

(b) Limited knowledge and capacity of associations of persons with albinism around the world to engage with human rights mechanisms;

(c) Little information, scarce data and incomplete reports on cases of discrimination on specific grounds;

(d) Scarcity of reliable data on cases of killings of and attacks[43] against persons with albinism in countries other than Burundi, Côte d'Ivoire or Tanzania, where there is a higher prevalence of albinism, but also a more active and better skilled civil society. The lack of information makes it difficult for potentially relevant special procedures mandate-holders to give attention to the issue within their respective mandates, including the Special Rapporteurs on torture and other cruel, inhuman or degrading treatment or punishment, on racism and related intolerance, education, disability, health, violence against women and violence against children. Similarly, the secrecy surrounding witchcraft and the underground nature of the market associated with the trafficking of persons and organs make it difficult to find evidence relevant to the mandates of the Special Rapporteur on the sale of children and the Special Rapporteur on trafficking in persons;

(e) Further, the scope of certain special procedures mandates prevents the mandate-holders from addressing the issue. For example, persons with albinism do not fall under the internationally accepted definition of minorities, which is limited to national, ethnic, religious or linguistic minorities,[44] and do not fall therefore within the scope of the mandate of the Special Rapporteur on minority issues. While the definition of "minority" is currently under review, it is unclear at this point whether the new definition will accommodate persons with albinism;

(f) Human rights challenges associated with albinism are multi-layered and are not currently being addressed in a comprehensive and sustainable manner by any human rights mechanism. In addition to the fact that they do not fall within the scope of the current definition of minorities, persons with albinism often suffer from poor eyesight and are prone to developing skin cancer, but cannot or would not want to be classified as persons with disabilities, as that would mean adding another layer of labelling and discrimination to which they may be subjected. They are attacked and tortured, and their body parts and organs are trafficked and sold owing to the myths and misconceptions surrounding albinism. Yet the protection afforded to persons with albinism by international human rights treaties does not cater for their special needs or the complexities they face, while existing special procedures can only partly address the situation of persons with albinism from a particular and limited angle to the extent that the scope of their mandates allows.

IV. Findings and recommendations

60. Persons with albinism have special needs. In addition to issues pertaining to the rights to life and security of person, it is necessary to address their special needs in terms of education due to their poor eyesight as well as their special health needs, particularly in the area of skin cancer prevention. The situation of human rights of persons with albinism should therefore be addressed in a holistic manner.

[43] It should be noted that ritual killings and attacks remain undocumented and unreported, owing to the code of silence surrounding such crimes and the vulnerability of the targeted population.

[44] See United Nations Declaration on the Rights of Persons Belonging to National or Ethnic, Religious and Linguistic Minorities, adopted by General Assembly resolution 47/135 of 18 December 1992.

The severity of the violations of the human rights of persons with albinism and the particular vulnerability of that segment of the population requires States not only to take a more active role to protect them, but also to take effective measures to eradicate poverty and improve enjoyment by persons with albinism of all their rights.

61. There is increased engagement of international and regional mechanisms with the issue of persons with albinism. Efforts however continue to be fragmented and only partially address the complexity of the human rights challenges that persons with albinism face. A more sustainable response, to bridge protection gaps and to ensure accountability for human rights violations committed against persons with albinism, is required.

A. States

62. States are the prime guardians of the human rights of all persons within their jurisdictions. States should have protection measures against practices such as attacks against persons with albinism and should comply with their international obligations concerning human rights, which are enshrined in both local laws and international human rights legal instruments. With regard to the latter, special mention should be made of the Convention on the Rights of the Child (see in particular articles 19 to 23), the Convention against Torture, the African Charter on the Rights and Welfare of the Child, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights. The existing body of international human rights law in terms of general human rights, standards on non-discrimination, equality and human dignity require effective implementation so as to protect and preserve the rights to life and to security of persons with albinism, as well as their right not to be subjected to discrimination, torture and ill-treatment.[45]

63. Clear laws criminalizing and punishing acts of violence against persons with albinism should be enacted. States need to clarify ambiguities where they exist in laws relating to witchcraft and traditional health practice, including through the effective regulation of the licenses of traditional healers and witchdoctor and a clear ban on the use of harmful practices. Attacks against persons with albinism should also be considered as an aggravated form of the crime, incurring a more severe punishment so that additional deterrence may be achieved.[46]

64. It should be stressed that simply promulgating laws is not enough to prevent violence. They should be implemented. Current laws against assault and murder tend to provide persons with albinism with minimum protection of their rights to life and security of person. Without effective implementation of those laws, States may become complicit in such attacks by enabling a reign of impunity and perpetuating fear of attack in the lives of persons with albinism. Hence, laws should be accompanied by concrete measures that would facilitate their implementation, such as advocacy and the training of law enforcement personnel and judicial authorities.

65. In order to respond to violence and discrimination against persons with albinism and address their root causes, a multipronged and holistic approach is necessary, involving protection and accountability measures in addition to broad public education campaigns.[47]

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[45] Outcome report of the Expert Meeting on Persons with Albinism: Violence, Discrimination and Way Forward, 24 September 2014, para. 54.

[46] Ibid., para. 70.

[47] Outcome report of the Expert Meeting on Persons with Albinism: Violence, Discrimination and Way Forward, 24 September 2014 (see footnote 15), para. 52.

Accountability measures should include successful prosecution and the guarantee of redress in the form of compensation and rehabilitation.

66. States should fight impunity and ensure that cases of violence and attacks are prosecuted successfully. Publicizing the verdicts of prosecutions will serve as deterrence and, in effect, protect persons with albinism while granting them legal redress and justice for the attacks. Ensuring registration of birth is also an important measure in the fight against impunity, as it will remove the invisibility of children with albinism. It is equally indispensable to evaluate the needs of persons with albinism and plan for the basic social services to which they are entitled.[48]

67. The protective role of the family should be supported. Parents and caregivers, as well as members of the extended family, play a central role in the protection of children with albinism. They need to be sensitized and engaged. There is also a need to empower children to prevent and address incidents of violence against them.[49]

68. Active public education and awareness-raising campaigns must be launched and sustained. Given the powerful potential of such campaigns for dispelling superstition and misinformation about albinism, they remain indispensable tools for curbing violations of the human rights of persons with albinism. They should aim at combating prejudice, superstition, misconception and stigma, with a view to diminishing the multiple and intersecting forms of discrimination affecting persons with albinism. States bear the ultimate responsibility for such attitudes and practices. A gradual approach may be adopted, by which States would first target specific key groups such as law enforcement officers, members of the judiciary, educators, social workers, medical service providers, and the families and communities of persons with albinism. Further, it is important that States include in their educational curricula, in a standardized manner, courses to instruct people on the rights of persons with albinism.[50]

69. In raising awareness of the problems through the mass media, both traditional and social media will be crucial in highlighting the issues faced by persons with albinism, including marginalization, stigmatization and discrimination, and could also contribute positively to protecting their rights by directing public opinion to the core of the problem, sensitizing the population and collectively searching for a solution to help protect persons with albinism. Television campaigns to demystify perceptions about persons with albinism and promote positive stories about them are one of the tools that could be used.

70. Greater attention will need to be given to supporting community level public campaigns through a wider use of community radio. When planning and implementing community level responses, there is a need to take into consideration the prominent community role played by traditional health practitioners involved in witchcraft.[51]

71. Resources, both financial and otherwise, are important for the success of any effort to improve the lives of persons with albinism. Taking into consideration that persons with albinism are disproportionately affected by poverty, owing to the discrimination and marginalization they face, there is a need for resources to develop activities designed to decrease and eliminate prejudice and create an environment conducive to respect for their rights and dignity.

72. There is a need for a comprehensive strategy to guarantee the protection of persons with albinism, notably in those countries where attacks have been reported. Such a strategy

[48] Ibid., para. 63.
[49] Ibid., paras. 66–67.
[50] Ibid., para. 57.
[51] Ibid., para. 60.

should be developed and implemented in coordination with, and with the support of, State authorities, various sectors of society, key stakeholders and civil society, as well as persons with albinism. Key non-governmental organizations such as Under The Same Sun and the World Albinism Alliance are important actors in that endeavour.

73. The commitment of all stakeholders to combat violence and discrimination against persons with albinism is critical. It is important to involve religious leaders who are well respected and influential in their communities and are in a position to provide followers with guidance on the issue of respect for the human rights and dignity of persons with albinism.[52]

B. International community

74. International and regional mechanisms should continue to give the necessary attention to the issue. Some of its facets can be integrated across existing human rights mechanisms, but credible data on cases of attacks and discrimination in several countries are few and far between or not entirely reliable.[53] Action should be taken to gather such information in order to put in place effective preventive and remedial action. Gathering information should be an independent process and ought not to be expected of existing special procedures mandate holders, as it is beyond their current scope and capacity.

75. Therefore it is necessary to consider setting up a specific dedicated mechanism to work on ending violence against persons with albinism and the structural and multi-layered discrimination they face. A large number of the answers to the questionnaire of the Advisory Committee called for the establishment of such a mechanism. A call for a specific and dedicated special procedure was also made by the participants at the expert meeting.

76. The special procedure would initiate and foster a holistic approach to the issue. Further, the mandate-holder would have better access to information, improved understanding of albinism both regionally and globally, and could initiate as well as follow up on concrete measures taken on the ground, through regular field visits and cooperation with authorities, civil society and other key stakeholders.

77. In conclusion, a dedicated special procedure mandate would be a first step towards ensuring an effective, comprehensive and more sustainable response to the human rights violations faced by persons with albinism.

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[52] Ibid., para. 58.

[53] See Under The Same Sun (UTSS), "Reported attacks of persons with albinism" (PWA) — Summary, available from www.underthesamesun.com/sites/default/files/Attacks%20of%20PWA%20-%201%20page_0.pdf.